PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (http://bmjopen.bmj.com/site/about/resources/checklist.pdf) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

| TITLE (PROVISIONAL) | Management of erectile dysfunction after prostate cancer treatment |
|---------------------|--|
| | - cross-sectional surveys of the perceptions and experiences of |
| | patients and healthcare professionals in the UK |
| AUTHORS | Dyer, Amy; Kirby, Mike; White, I. D.; Cooper, Alison |

VERSION 1 – REVIEW

| REVIEWER | Penny Wright |
|-----------------|---------------------|
| | University of Leeds |
| | UK |
| REVIEW RETURNED | 23-May-2019 |

| GENERAL COMMENTS | This paper provides a basic simple description of men's experience |
|------------------|---|
| | of erectile dysfunction services/ support and what Health Care |
| | Professionals (HCP) offer. It does not provide an in-depth |
| | interpretation of these descriptive outcomes. The survey methods |
| | method used mean the results cannot be generalised. The paper |
| | would benefit from more detail in part and less repetition (tables and |
| | text) in other parts. |
| | Abotes et |
| | Abstract |
| | Needs reordering in that the setting provides results (see below). |
| | Introduction |
| | This was a clear and well written introduction with good referencing. |
| | I wondered why there was no mention of disease monitoring as a |
| | 'treatment option' (Active Surveillance, Watchful waiting). There is |
| | new NICE guidance just published which may not have been |
| | available at the time of submission which they may want to include |
| | reference to https://www.nice.org.uk/guidance/NG131. |
| | Methods |
| | This section lacked detail and needs working on. |
| | 1. Having subheadings such as design, participants, measures etc. |
| | would help with navigation in this section and in the results section. |
| | 2. There was very limited information about the actual surveys |
| | administered (patient and HCP). The authors said they were co- |
| | designed with patients but there is not a lot more information available. |
| | available. a. How many questions in each survey? |
| | b. How long were participants told it would take to complete? |
| | c. What did the introduction state in terms of who was eligible to |
| | complete it? Were only men who had current problems with erectile |
| | function asked to participate or were men who had had problems in |
| | the past which were now resolved also included? |
| | d. Were the surveys piloted at all – what kind of simple |
| | reliability/validity checks were done? |
| | e. What do they mean by 'response options' were varied to reduce |
| | bias? Was this the case on the paper one? |
| | f. Was patient educational status asked about? |
| | g. What about co-morbidities (e.g. heard disease or diabetes)? |
| | h. Were the men asked about provision of written information/leaflets? |
| | |
| | i. Were HCPs asked about training, access to resource, guidance? |

j. Were HCPs asked what sex they were and how old they were?
k. Were HCPs asked how long they had been in their current post?
A much clearer description of these surveys and how they were constructed is required. I think they should be included as supplementary data.

3. Statistical analyses

I presume the same approach was taken with the HCP descriptions but by professional group. Was any analysis done by sex of HCP or by time since diagnosis/treatment for the men with Prostate cancer?

4 Fthics

There is no mention of any kind of ethical review. Although this would not have required an IRAS application I would have thought some kind of ethics review process was required. If not a statement should be given explaining why not.

The description of the participants should not be included in the methods, it is a result (page 4 lines 10-13; lines 20-23).

Results

The participants should be described here. I did not like having to look at the supplementary tables to get this basic description of those who had taken part. A bigger table with the HCP descriptives included also would be useful to aid interpretation. The would mean some of the duplication in the text could be lost.

- 5. Does the team have any idea of how many HCPs use the routes to engaging HCPs to participate. How did the weighting work.? I guess a response rate is difficult to estimate but checking with the English numbers of GPs currently (34,510 FTE) for example, the participation of 115 GPs across the UK is quite low.
- 6. Tables should not be split into a, b, c. These should be blocked together. I realise that the authors are at their limit with tables and figures and I have suggested including supplementary table 1 in the main manuscript which is pushing this over the limit but I think it is important to include.
- 7. Table 1 a the response options are very numerous. It tokl me a while to realise how the response options most time, sometimes and a few times differed. Would it be worth collapsing some of these options to make easier reading?
- 8. As stated earlier there is considerable repetition in the text and the tables. For example Table 2b 40% of men were offered treatment within three months and in the text (page 7 line 12) Two fifths of men (199(40%)....
- 9. Page 8 lines 13-14 I don't understand the numbers in the monitoring of treatment section. In Table 2b it looks like 293 men were offered treatment (110 not offered treatment) therefore how come the denominator on page 8 line 13 is 402? Should it not be 128/293 (45%)? Could you put this at the bottom of table 2 and split by treatment grouping as for other two (a, b)?
- 10. Page 8 line 12 does the 77% refer to not being asked questions, or to complete a questionnaire (either, or or both)? Confusing to the reader.
- 11. Figure 2 impossible to read meaningfully.
- 12. It would have been interesting to see if there were any differences found by time since diagnosis/ treatment as it may be that communication/resource/attitudes have changed over time. Almost half of the men had their treatment more than ten years ago. Are things the same for all men irrespective of time?
- 13. Likewise it would be interesting to see if the sex of the HCP

made a difference to what was addressed with the men.

Discussion

- 14. I thought the discussion read well with relevant referencing putting the findings into context.
- 15. The study goes back over many years recall and I do wonder if things have changed at all. Is there any literature which could shed light on this that could be referenced?
- 16. As stated earlier if it was possible to look at the men treatment ten or more years ago and compare their experiences with men treated or recently that might help inform the discussion.
- 17. Many of the men will now be ten years older than at time of diagnosis what impact may this have had on erectile issues?
- 18. If there is information available what impact might co-morbidity such as heart disease or diabetes have had? These conditions are likely to increase with age. How can you tease apart (do you need to) the problems associated with different conditions?
- 19. What about mentioning the 6 monthly cancer review in primary care as an opportunity for primary care to mention erectile dysfunction issues how might it fit?
- 20. The limitations of the study are a main concern. Although some are listed here such as recall problems and the convenience nature of the sample there are others.
- a. Just how representative of the prostate cancer population are these men? They will have found out about the study in the main from online resources does this not mean a skew in the sample (possibly better educated, younger etc).
- b. Do you know anything about ethnicity of the men and how this may impact on their experiences?
- c. Although the sample size of health care professionals is reasonable just how self-selected were they? The suthors state there is a mismatch between what they say and what the men experience might it not be that these professionals are more interested anyway in these types of issue? It is a possibility.
- 21. Overall how do the authors think things have changed over the last few decades regarding this, if at all?

| REVIEWER | Erik Wibowo |
|-----------------|----------------------------------|
| | University of Otago, New Zealand |
| REVIEW RETURNED | 10-Jun-2019 |

GENERAL COMMENTS

Thank you for the opportunity to review this paper. This is an important study to capture data about communication between healthcare providers and patients about erectile dysfunction management. Below are my comments:

- 1. Please clarify what ethic board/committee provides the Ethic Approval.
- 2. The Methods section needs more information with regard to the questionnaires used. For example, how many questions were included, did it contain any validated questionnaires, how long it takes.
- 3. Table 1b is for "who asked the first questions about your erections before treatment?". The second last line is "You". Could the author clarify what this means?
- 4. Table 2 b asks about "how long after prostate cancer treatment were you offered treatment...?" Do the authors capture data on whether patients were counseled about ED treatment options BEFORE receiving prostate cancer treatment?
- 5. I would suggest to give sub-headings for the Discussion for better readability.

- 6. Figure 6 appears to have complete black background on my file. I don't know if this is intended to be this way, or if there was a technical glitch. Please disregard my comment if this is a glitch. Otherwise, this needs a white background.
- 7. Figure 3 could be larger.
- 8. Supplementary Fig 3. I'm really surprised that only 2% of patients received counseling. This is very low. Is this related to the medical coverage in the UK? Could cost be a barrier if this is not covered by insurance? The authors also mentioned about the Movember's TrueNTH program. This needs to be taken with caution as there is yet any published information that the program is effective in helping patients manage ED after prostate cancer treatment. Even if there is a short-term benefit, there is no information on, for example, patients' compliance in treatment in a long term. Meanwhile it's now well known that most patients withdraw from ED treatment for various reasons.
- 9. Did the authors capture data on the use of penile implant or sex toys?

VERSION 1 – AUTHOR RESPONSE

Reviewers' comments with author replies (shown in purple)

Additional author changes:

Since submitting the manuscript, the National Prostate Cancer Audit - Organisational Audit 2019 have been published. A mention of these results, and reference number 41, have been added into the discussion. The 2018/19 results are consistent with the 2016/17 results, so the message in the discussion is unchanged by the recent data.

Editorial requests:

- Please include the study design in the title.

The term "cross-sectional qualitative" has been added into the title so it now reads "Management of erectile dysfunction after prostate cancer treatment – cross-sectional qualitative surveys of the perceptions and experiences of patients and healthcare professionals in the UK".

- Please include a copy of the STROBE checklist as a supplementary file, completed with page numbers indicating where each item can be found in your manuscript.

A STROBE checklist for cross-sectional studies has been included as supplementary file 2.

- Please include an ethical approval statement at the end of your paper, stating why it was not required for this study.

An 'Ethical approval statement' has been added to the end of the manuscript with more detail:

"This study did not require an application for ethical approval, in line with the NHS Research Ethics Committee decision tool (http://www.hra-decisiontools.org.uk/ethics/). The study was assessed and approved by Prostate Cancer UK's Policy & Campaigns Forum, consisting of men living with and after prostate cancer, and Leadership Team. By

completing the survey, respondents were consenting to be part of the study and were informed that their responses would be confidential and not used for any other purposes beyond this research study."

Reviewer(s)' Comments to Author:

Reviewer: 1

Reviewer Name: Penny Wright

Institution and Country: University of Leeds, UK Please state any competing interests or state 'None

declared': None declared

Please leave your comments for the authors below

Thank you for your comments.

This paper provides a basic simple description of men's experience of erectile dysfunction services/ support and what Health Care Professionals (HCP) offer. It does not provide an in-depth interpretation of these descriptive outcomes. The survey methods method used mean the results cannot be generalised. The paper would benefit from more detail in part and less repetition (tables and text) in other parts.

Abstract

Needs reordering in that the setting provides results (see below).

The abstract has been re-ordered so that the information on respondents now appears under the Results heading.

Introduction

This was a clear and well written introduction with good referencing. I wondered why there was no mention of disease monitoring as a 'treatment option' (Active Surveillance, Watchful waiting). There is new NICE guidance just published which may not have been available at the time of submission which they may want to include reference to https://protect-eu.mimecast.com/s/L41ACwGEiNLY1H9dyAN?domain=nice.org.uk.

Disease monitoring as a treatment option, and a reference to the NICE guidance on active surveillance, has been added into the introduction ("Active surveillance is also offered as an option to men with low-risk, and sometimes intermediate-risk, localised prostate cancer"). The NICE 2014 prostate cancer guideline reference has been updated to the 2019 version of the guideline in the reference list.

Methods

This section lacked detail and needs working on.

1. Having subheadings such as design, participants, measures etc. would help with navigation in this section and in the results section.

The sub-headings in the Methods section have been made clearer. The data on number of responses has been moved to the Results section (as per a later comment), so this now makes the results section shorter and therefore clearer to read.

- 2. There was very limited information about the actual surveys administered (patient and HCP). The authors said they were co-designed with patients but there is not a lot more information available.
- a. How many questions in each survey?
- b. How long were participants told it would take to complete?

The survey questions have been provided as a new supplementary file (Supplementary File 1).

The number of questions and time to complete has been added into the Methods section. Men's survey: "The survey consisted of a maximum of 48 questions and participants were told it would take 10 – 15 minutes to complete.". HCP surveys: "The primary care survey consisted of a maximum of 16 questions and the secondary care survey consisted of a maximum of 18 questions. All participants were told it would take 10 minutes to complete."

More information has been added to the Methods section regarding how patients and HCPs were involved in the study design and pilots ("Questions for both surveys were co-produced and piloted by men living with and after prostate cancer and HCPs, through virtual working groups and face-to-face workshops).

c. What did the introduction state in terms of who was eligible to complete it? Were only men who had current problems with erectile function asked to participate or were men who had had problems in the past which were now resolved also included?

This information is now included as part of Supplementary File 1. Participants were asked:

Q1. Please tick the statement that best describes you:

I'm a man who's been treated for prostate cancer, and I have had trouble getting or keeping an erection after treatment (the dataset used for analysis)

I'm a man who's been treated for prostate cancer, but I have not had trouble getting or keeping an erection after treatment

So if a man selected the first option, these would include both men with current ED problems and those who previously had ED problems which have now been resolved. This was the dataset that was used for analysis for the manuscript (n=546).

d. Were the surveys piloted at all – what kind of simple reliability/validity checks were done?

Yes, the surveys were piloted with men living with and after prostate cancer and HCPs, through virtual working groups and face-to-face workshops. This information has been added to the Methods section. During data analysis, only complete and non-duplicate surveys were included. This detail was previously included in the Methods but has now been moved into the Results sections, for both the men's and HCP's surveys, by adding 'complete responses'.

e. What do they mean by 'response options' were varied to reduce bias? Was this the case on the paper

one?

Response options were varied' is when the online survey platform randomises the order of the answer options. This avoids potential bias if participants were drawn to the top answer, for example. Therefore, automatically randomising the order of the answer options reduces this potential bias. Due to the nature of paper surveys, this option was not possible in this format (although only a small proportion of the data was from paper surveys). Further explanation on this has been added into the Methods section ("Where appropriate, the online survey platform randomised the order that response options for a question were displayed, in order questions and response options were randomized to reduce bias.")

- f. Was patient educational status asked about?
- g. What about co-morbidities (e.g. heard disease or diabetes)?
- h. Were the men asked about provision of written information/leaflets?

Information on educational status, co-morbidities and provision of leaflets were not asked in the men's survey.

i. Were HCPs asked about training, access to resource, guidance?

HCPs were not explicitly asked about current access to training, resources and guidance. However the below questions were asked to primary HCPs:

I am confident that my knowledge of prostate cancer (Q8) / ED (Q9) / the treatment options for ED (Q10) is sufficiently **comprehensive** to support men with prostate cancer (1)

I am confident that my knowledge of prostate cancer (Q8) / ED (Q9) / the treatment options for ED (Q10) is sufficiently **up to date** to support men with prostate cancer (2)

Extremely unconfident (1) / Apprehensive (2) / Satisfactory (3) / Confident (4) / Very confident (5)

As already stated in the Results section, "When asked what would help to improve their confidence, the most common responses were 'training/education', and 'further information/literature/online resources'." This is then picked up in the Management of ED in primary care section of the Discussion: "These issues seemed to reflect restricted access to treatments and services and lack of confidence in managing ED. This suggests a need for better targeted training and education, particularly for practice nurses."

j. Were HCPs asked what sex they were and how old they were?

Yes – the urologists and GPs were asked about gender and age. This information has now been provided in a new supplementary file (supplementary file 4). A reference to this table has been added into the 'Survey of primary and secondary healthcare professionals - Respondent characteristics' section of the Methods.

k. Were HCPs asked how long they had been in their current post? No, this question was not asked.

A much clearer description of these surveys and how they were constructed is required. I think they should be included as supplementary data.

The survey questions have been included as Supplementary File 1, for both men with prostate cancer and HCPs.

3. Statistical analyses

I presume the same approach was taken with the HCP descriptions but by professional group. Was any analysis done by sex of HCP or by time since diagnosis/treatment for the men with Prostate cancer?

By "same approach", I assume you are referring to the following from the Methods section: "For the survey of men with ED after prostate cancer treatment, responses were grouped and analysed by type of prostate cancer treatment received." This was not necessary in the analysis of the HCP surveys as they were already split by profession at the time of data collection. A sentence has been added to the end of the 'Statistical Analysis' section of the Results to explain this: "HCP data was already split by profession at the time of data collection. Data was then pooled to compare between professions."

Additions have made on GP data split by gender. This is covered in answer to question 13 in this document.

Analysis was done on the men's data by time since first/last treatment for prostate cancer. There were no findings of interest to include in the manuscript.

4. Ethics

There is no mention of any kind of ethical review. Although this would not have required an IRAS application I would have thought some kind of ethics review process was required. If not a statement should be given explaining why not.

As the reviewer states, this study did not require an application for ethical approval as per the criteria in the NHS Research Ethics Committee (REC) decision tool (http://www.hra-decisiontools.org.uk/ethics/).

An 'Ethical approval statement' has been added to the end of the manuscript with more detail:

"This study did not require an application for ethical approval, in line with the NHS Research Ethics Committee decision tool (http://www.hra-decisiontools.org.uk/ethics/). The study was assessed and approved by Prostate Cancer UK's Policy & Campaigns Forum, consisting of men living with and after prostate cancer, and Leadership Team. By completing the survey, respondents were consenting to be part of the study and were informed that their responses would be confidential and not used for any other purposes beyond this research study."

The description of the participants should not be included in the methods, it is a result (page 4 lines 10-13; lines 20-23).

This text has been moved to the start of the Results section for both the men's survey and the HCP's survey.

Results

The participants should be described here. I did not like having to look at the supplementary tables to get this basic description of those who had taken part.

The description of the participants has been moved from the Methods to the first paragraph of the Results in each of the men's and HCP's sections.

The table of respondent characteristics for the men's survey (previously Supplementary Table 1) has been moved into the main text and renumbered as Table 1. Some of the repetition in the text describing the characteristics has been deleted (sexual orientation, relationship status and country).

For clarity in Table 1, the answer options for year of first treatment have been renamed to show years since treatment.

A bigger table with the HCP descriptives included also would be useful to aid interpretation. This would mean some of the duplication in the text could be lost.

For HCPs, a table of respondent characteristics has been added as a new table (Table 4) and the repetition in the text describing the characteristics has been deleted.

- 5. Does the team have any idea of how many HCPs use the routes to engaging HCPs to participate. How did the weighting work? I guess a response rate is difficult to estimate but checking with the English numbers of GPs currently (34,510 FTE) for example, the participation of 115 GPs across the UK is quite low. It is not possible to know the response rates as these was provided to us by the companies who conducted the HCP surveys on our behalf. The HCP sample sizes were chosen on recommendation from the research companies (the names of which are included in the Methods).
- 6. Tables should not be split into a, b, c. These should be blocked together. I realise that the authors are at their limit with tables and figures and I have suggested including supplementary table 1 in the main manuscript which is pushing this over the limit but I think it is important to include.

Tables 1 and 2 have been blocked together and the a,b,c splits have been removed from both the tables and the manuscript text.

7. Table 1 a – the response options are very numerous. It took me a while to realise how the response options most time, sometimes and a few times differed. Would it be worth collapsing some of these options to make easier reading?

To make Table 1 clearer, the answer options 'sometimes (~50%)' and 'a few times (<50%)' have been merged into a single row labelled 'sometimes (<50%)' as the meaning is very similar.

8. As stated earlier there is considerable repetition in the text and the tables. For example Table 2b 40% of men were offered treatment within three months and in the text (page 7 line 12) Two fifths of men (199(40%)....

This is referring to the table now numbered as Table 3. Timely access to ED treatment is a key issue which is why it has been drawn out of the table into the main text. It is important to show these key stats as a table and in the main text. There are additional stats in what is now Table 3 which aren't mentioned in the text.

9. Page 8 lines 13-14 I don't understand the numbers in the monitoring of treatment section. In Table 2b it looks like 293 men were offered treatment (110 not offered treatment) therefore how come the denominator on page 8 line 13 is 402? Should it not be 128/293 (45%)? Could you put this at the bottom of table 2 and split by treatment grouping as for other two (a, b)?

This is referring to the table now numbered as Table 3.

503 responses were received to the question "Q27. How long after prostate cancer treatment, if at all, were you offered treatment to help you get or keep an erection?" which is shown in the second half of now Table

3. Of these 503, 110 indicated they were offered no treatment ("Not at all"), leaving a total of 393. I think this is the number you are referring to above, however you calculated this as 293, rather than 393.

The reason why the denominator is 402 on page 8, rather than 393, is because 9 more men answered either yes/no/unsure to the question "Q37. Did the treatment(s) you were prescribed [for ED] meet your needs?" compared with the previous question (Q27). So the denominators for both questions are correct in the text.

10. Page 8 line 12 - does the 77% refer to not being asked questions, or to complete a questionnaire (either, or both)? Confusing to the reader.

This was referring to the use of questionnaires. The sentence has been re-worded to "Over three quarters of respondents (n=374/484; 77%) said they were not asked to complete a questionnaire about their erections, such as the SHIM or IIEF, during ED treatment."

11. Figure 2 impossible to read meaningfully.

I believe this is due an error which occurred when the journal website merged all the submitted files into a single PDF for the reviewers – the background colour appears black. The separate image file, which was also uploaded for this figure, displays correctly.

12. It would have been interesting to see if there were any differences found by time since diagnosis/ treatment as it may be that communication/resource/attitudes have changed over time. Almost half of the men had their treatment more than ten years ago. Are things the same for all men irrespective of time?

Analysis was done on the men's data by time since first/last treatment for prostate cancer. There were no findings of interest to include in the manuscript.

To clarify, at the time the study was conducted, 85% of the respondents had their first prostate cancer treatment in the last 9 years (Table 1). The sample size for those men treated >10 years ago was too small to make a comparison with the <10 years group.

13. Likewise it would be interesting to see if the sex of the HCP made a difference to what was addressed with the men.

Gender was asked in the GP and urologist HCP surveys (this data is now included as Table 4). The most interesting data, on gender split for GPs regarding who initiates the conversation regarding ED (them vs the patient), has now been added into the 'Discussions about ED' section of the Results. A comment on this has also been added to the 'Communication between HCPs and patients' section of the Discussion.

Discussion

- 14. I thought the discussion read well with relevant referencing putting the findings into context. Thank you.
- 15. The study goes back over many years recall and I do wonder if things have changed at all. Is there any literature which could shed light on this that could be referenced?

In brief, unfortunately, the issues around erectile dysfunction after prostate cancer treatment have not improved over the last decade:

In terms of EF outcomes after surgery, the following is already included in the Introduction:

"A recent review from a high-volume centre suggested that despite the advancements in surgical and post-operative care, erectile function outcomes after radical prostatectomy have not improved over the last decade and more efforts are needed to improve patient's care after radical prostatectomy.[19]"

Less longitudinal data is available on access to ED treatment and support services and whether patient's find these effective (hence a reason to do this study). The access data from National Prostate Cancer Audit data is already included in the Discussion, however, as discussed, this does not always reflect reality. The large LAPCD study,

described in the Introduction, highlighted that issues with sexual function are currently highly prevalent in the prostate cancer population.

16. As stated earlier if it was possible to look at the men treatment ten or more years ago and compare their experiences with men treated or recently that might help inform the discussion.

At the time the study was conducted, 85% of the respondents had their first prostate cancer treatment in the last 9 years (Table 1). The sample size for those men treated >10 years ago was too small to make a comparison with the <10 years group.

17. Many of the men will now be ten years older than at time of diagnosis – what impact may this have had on erectile issues?

It is known that erectile function declines with age. However, the questions in the survey focussed on the men's experiences before and after their treatment for prostate cancer, rather than on their current erectile function.

18. If there is information available what impact might co-morbidity such as heart disease or diabetes have had? These conditions are likely to increase with age. How can you tease apart (do you need to) the problems associated with different conditions?

Yes, co-morbidities have been shown to increase with age which, in turn, both increase the likelihood of erection function problems. Over the last decade, radical prostatectomy patients have got older and therefore have worse erectile function. This is shown in the following paper already cited in the manuscript:

19. Capogrosso P, Vertosick EA, Benfante NE, et al. Are We Improving Erectile Function Recovery After Radical Prostatectomy? Analysis of Patients Treated over the Last Decade. Eur Urol 2019;75:221–8. doi:10.1016/j.eururo.2018.08.039

However, even when age and co-morbidities are accounted for, erectile function after prostate cancer surgery, for example, has still not improved over the last decade (shown in the above paper).

19. What about mentioning the 6 monthly cancer review in primary care as an opportunity for primary care to mention erectile dysfunction issues – how might it fit?

Yes, this is a good suggestion. The role of the CCR, and how effective they are for patients, has been added to the 'Communication between HCPs and patients' section of the Discussion.

- 20. The limitations of the study are a main concern. Although some are listed here such as recall problems and the convenience nature of the sample there are others.
- a. Just how representative of the prostate cancer population are these men? They will have found out about the study in the main from online resources does this not mean a skew in the sample (possibly better educated, younger etc).

This study is a good representation of the prevalence breakdown of men living with and after prostate cancer (time since diagnosis). However, the study sample is considerably younger than the prostate cancer population in general. Text has been added on this into the 'Respondent characteristics' section of the men's survey Results, the 'Limitations of the study' section of the Discussion and the Article Summary bullet points.

- b. Do you know anything about ethnicity of the men and how this may impact on their experiences? No, data on ethnicity was not collected in this study.
- c. Although the sample size of health care professionals is reasonable just how self-selected were they? The authors state there is a mismatch between what they say and what the men experience might it not be that these professionals are more interested anyway in these types of issue? It is a possibility.

The HCPs were selected from a large panel of HCPs who had stated an interest in taking part in research. They were selected at random from the panel in order to take part in this survey. So it would not be possible for HCPs with a particular interest in prostate cancer and ED to have been more likely to have been selected for this study, over other HCPs without a particular interest.

21. Overall how do the authors think things have changed over the last few decades regarding this, if at all?

Please see my response to question 15.

| Reviewer: 2 | 2 |
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Reviewer Name: Erik Wibowo

Institution and Country: University of Otago, New Zealand Please state any competing interests or state

'None declared': None declared

Please leave your comments for the authors below

Thank you for the opportunity to review this paper. This is an important study to capture data about communication between healthcare providers and patients about erectile dysfunction management. Below are my comments:

Thank you for your comments.

1. Please clarify what ethic board/committee provides the Ethic Approval.

An 'Ethical approval statement' has been added to the end of the manuscript with more detail:

"This study did not require an application for ethical approval, in line with the NHS Research Ethics Committee decision tool (http://www.hra-decisiontools.org.uk/ethics/). The study was assessed and approved by Prostate Cancer UK's Policy & Campaigns Forum, consisting of men living with and after prostate cancer, and Leadership Team. By completing the survey, respondents were consenting to be part of the study and were informed that their responses would be confidential and not used for any other purposes beyond this research study."

2. The Methods section needs more information with regard to the questionnaires used. For example, how many questions were included, did it contain any validated questionnaires, how long it takes.

This information has been added into the Methods (survey length and time) and the survey questions have been added as a new Supplementary File 1. A STROBE checklist has also been added as a new Supplementary File 2.

3. Table 1b is for "who asked the first questions about your erections before treatment?". The second last line is "You". Could the author clarify what this means?

The "you" here is referring to the patient himself – so the man with ED after prostate cancer treatment. This is because the questions and answers shown here are as they were exactly asked in the survey which the men completed. This has been clarified in the now Table 2 (which was previously Table 1) by adding '[the patient]' or '[the patient's]' into the questions and response options.

4. Table 2 b asks about "how long after prostate cancer treatment were you offered treatment...?" Do the authors capture data on whether patients were counselled about ED treatment options BEFORE receiving prostate cancer treatment?

(Table 2b referred to in this question is now Table 3)

This is covered in an earlier section of the Results called 'Men's experiences prior to prostate cancer treatment' and Table 2 (previously Table 1). Data is included on which HCP was the first to question men about their erectile function before prostate cancer treatment, whether standardised erectile function questionnaires were used, whether it was explained to men that ED might be a side effect of their treatment (the most relevant in relation to your question on counselling) and whether partners were included in these discussions.

5. I would suggest to give sub-headings for the Discussion for better readability.

Sub-headings have been added to the Discussion.

6. Figure 6 appears to have complete black background on my file. I don't know if this is intended to be this way, or if there was a technical glitch. Please disregard my comment if this is a glitch. Otherwise, this needs a white background.

I believe the reviewer is referring to Figure 2, rather than Figure 6. As mentioned above in reply to reviewer 1, I believe this is due an error which occurred when the journal website merged all the submitted files into a single PDF for the reviewers – the background colour appears black. The separate image file, which was also uploaded for this figure, displays correctly.

7. Figure 3 could be larger.

As above, this occurred when the journal website merged all the submitted files into a single PDF for the reviewers. The size will be appropriate in the final version.

8. Supplementary Fig 3. I'm really surprised that only 2% of patients received counselling. This is very low. Is this related to the medical coverage in the UK? Could cost be a barrier if this is not covered by insurance? (Supplementary File 3 referred to in this question is now Supplementary File 4)

This is a low proportion of the patients. The below are extracts from the NICE guideline for prostate cancer which cover counselling – in the wide sense of the term – on sexual function issues for men being treated for prostate cancer. So whilst only a small proportion of men may actually be referred to a different HCP for

'psychosexual counselling', men will be having conversations of this nature along their treatment pathway from various HCPs (data in our study has shown this to be the case). All the below support options are included free of charge on the NHS in the UK.

Decision support

- 1.1.12 Tell people with prostate cancer and their partners or carers about the effects of prostate cancer and the treatment options on their:
 - sexual function
 - physical appearance
 - continence
 - other aspects of masculinity.

Support people and their partners or carers in making treatment decisions, taking into account the effects on quality of life as well as survival. [2008]

- 1.1.13 Offer people with prostate cancer, and their partners or carers, the opportunity to talk to a healthcare professional experienced in dealing with psychosexual issues at any stage of the condition and its treatment. [2008]
- 1.3 Localised and locally advanced prostate cancer
- 1.3.1 Before radical treatment, explain to people and, if they wish, their partner, that radical treatment for prostate cancer will result in an alteration of sexual experience, and may result in loss of sexual function. [2008, amended 2014]

Managing adverse effects of radical treatment

Sexual dysfunction

1.3.33 Offer people who have had radical treatment for prostate cancer access to specialist erectile dysfunction services. [2008, amended 2014]

Managing adverse effects of hormone therapy

Sexual dysfunction

- 1.4.8 Ensure that people starting androgen deprivation therapy have access to specialist erectile dysfunction services. [2014]
- 1.4.9 Consider referring people who are having long-term androgen deprivation therapy, and their partners, for psychosexual counselling. [2014]

Taken from: https://www.nice.org.uk/guidance/ng131/chapter/Recommendations.

The authors also mentioned about the Movember's TrueNTH program. This needs to be taken with caution as there is [not] yet any published information that the program is effective in helping patients manage ED after prostate cancer treatment. Even if there is a short-term benefit, there is no

information on, for example, patients' compliance in treatment in a long term. Meanwhile it's now well known that most patients withdraw from ED treatment for various reasons.

This sentence in the Discussion has been amended to "Although not yet proven to be effective, novel support approaches have been developed in a bid to tackle this problem such as the Movember Foundation's TrueNTH initiative...."

9. Did the authors capture data on the use of penile implant or sex toys?

ED treatment data was collected in Q32 (see Supplementary File 1) of the men's survey. No respondents answered that they had a penile implant. Penile implant availability was included in the HCP's surveys. This is covered in the 'Management of ED' section of the HCP survey results and in Figure 3: "GPs were much less likely than urologists to use second- or third-line treatments, including VED (15% vs 86%), intracorporeal injections (35% vs 86%), intraurethral PGE-1/alprostadil (17% vs 58%), **penile implants (9% vs 28%)**, combination therapy (1% vs 50%), psychosexual therapy (12% vs 24%) and pelvic floor exercises (12% vs 20%) (Figure 3)."

No data was collected on the use of sex toys.

REVIEWER

REVIEW RETURNED

GENERAL COMMENTS

VERSION 2 - REVIEW

Penny Wright

| IVEAICAACIV | r entry wright |
|------------------|---|
| | University of Leeds |
| | UK |
| REVIEW RETURNED | 23-Jul-2019 |
| | |
| GENERAL COMMENTS | The authors have responded well to the comments provided. The paper is much clearer and easier to navigate. I have a couple of comments only to ask them to consider. 1. The title and in the text the surveys are referred to as 'cross sectional qualitative surveys'. This is not correct. A survey by its nature is a quantitative methodology unless the majority of questions/items are free text and are going to be analysed using a thematic/content analysis. Looking at supplementary file 1 and just by reading the manuscript it is clear this is a quantitative survey not qualitative. Please amend this. 2. In the limitations I think the fact that no ethnicity data were collected should be mentioned. Prostate Cancer has a higher incidence in black British men (1 in 4) than white British men (1 in 8). It may be that black men are more reticent about discussing sexual problems than white men. It would have been interesting and important to include ethnicity data in the survey to explore any |
| | potential differences. |
| | There seems to be a glitch in the system which is turning the letter |
| | 'n' to the letter 'g', so that for example 'men' become 'meg'. |
| | <u></u> |
| REVIEWER | Erik Wibowo |

were several places with minor typos.

I am happy to accept this revised manuscript for publication. There

University of Otago

05-Aug-2019

VERSION 2 – AUTHOR RESPONSE

In response to reviewer 1's comments, we have removed all mentions of the word 'qualitative' from the title and manuscript. Thank you for this comment. Also, we have added a sentence into the introduction about the known risk factors for prostate cancer, including ethnicity. We have also added a sentence on the fact that ethnicity data was not collected into the 'Limitations' section of the Discussion. In terms of the 'glitch' which means the letter 'n' is showing as the letter 'g' – we are not experiencing this issue so we assume any issues like this will be resolved during the publication process.

In response to reviewer 2's comment, we have proof-read the manuscript again and corrected several small grammatical errors and typos.